

NPM 02: *The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. (CSHCN survey)*

Annual Objective and Performance Data	Tracking Performance Measures (Sec 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii))				
	2000	2001	2002	2003	2004
Annual Performance Objective				67.6	68.6
Annual Indicator			66.6	66.6	66.6
Numerator			47,819	47,819	47,819
Denominator			71,816	71,816	71,816
Is Data Provisional or Final				Final	Final
	2005	2006	2007	2008	2009
Annual Performance Objective	69.6	70.6	71.6	72.6	73.6

Notes - 2002

Source: SLAITS CSHCN Survey. Numerator: Weighted Wisconsin-specific data. Denominator: Weighted Wisconsin-specific data. Data issues: These are new data from the national SLAITS CSHCN Survey. Wisconsin data are weighted; however, the actual number who were asked if they partner in decision making and are satisfied with the services they receive was 275. Because of the small sample size, Wisconsin will be examining other sources of information for future years to supplement the national data.

Notes - 2003

Source: NCHS SLAITS CSHCN module; the data reported in 2002 pre-populated the data for 2003 for this performance measure.

Notes - 2004

The data reported in 2004 are pre-populated with the data from 2003 for this performance measure.

a. Last Year's Accomplishments

1. Information and Referral Satisfaction Survey--Direct Health Care Services--CSHCN

The information and referral satisfaction survey is an ongoing survey that continued throughout 2004 in order to assure the services, provided through the CSHCN Program, are meeting the needs of the families. An "Annual Program Evaluation Report" was developed and distributed during the last six months of 2004. The report provides a satisfaction summary with the information and referral services received from the CSHCN Program.

2. Financial support to County Parent Liaisons--Infrastructure Building Services--CSHCN

Financial support was provided to over 70 CPLs to continue involvement in activities that positively impact policies, programs, services and supports regarding children with special health care needs.

3. Employment of State Parent Consultant and Regional CSHCN Center Parent Coordinators--Infrastructure Building Services--CSHCN

The CSHCN Program integrated the Parent Consultant role in several staff positions. More emphasis was placed to promote parent involvement in the Medical Home Initiative to assure a family centered perspective is maintained and parent partners are supported throughout the process. In addition, each of the five Regional CSHCN Centers employed a parent coordinator. The Wisconsin First Step Hotline employed parents with children with special health care needs to provide information and referral. There was continuing support for a CPL in each of Wisconsin's 72 counties.

4. Participation of families on advisory committees to the MCH and CSHCN Program--Infrastructure Building Services--CSHCN

The role of families has been strengthened as they participate on the NBS Advisory Committee, EHDI Planning Workgroup, Council for Birth Defect Prevention and Surveillance, and MCH Advisory Committee. Title V has become a leader in assuring parents are represented on advisory committees and has helped other programs locate and include a parent in an advisory capacity.

5. Parent input into the MCH Block Grant Application--Infrastructure Building Services--CSHCN

We requested the number of parents providing input into the 2005 MCH Block Grant Application by requesting input from over 500 parents who attended the annual families conference called Circles of Life. Additionally, methods of gathering parent input for the Needs Assessment was discussed as we began the process this past fall.

6. Collaboration on the implementation of a Family to Family Health Information Center grant with Family Voices--Population-Based Services--CSHCN

In 2004, Family Voices received a CMS grant to develop the above named Center. The CSHCN Program was actively involved in the planning and implementation of activities related to this grant including the development of fact sheets for families, developing training to families regarding health benefits and coordinating information and assistance services across the state so that families can access information easier.

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1. Information and Referral Satisfaction Survey	X			
2. Financial Support to County Parent Liaisons				X
3. Employment of State Parent Consultant and Regional CSHCN Center Parent Coordinators				X
4. Participation of families on advisory committees to the MCH and CSHCN Program				X
5. Parent input into the MCH Block Grant Application				X
6. Collaboration on the implementation of a Family to Family Health Information Center grant with Family Voices			X	

b. Current Activities

1. Information and Referral Satisfaction Survey--Direct Health Care Services--CSHCN

The CSHCN Program will continue to assure families are satisfied with those services received from the Regional CSHCN Centers including information and referral, parent to parent support and service coordination.

2. Financial support to County Parent Liaisons--Population-Based Services--CSHCN

Financial support is continuing to be provided to CPLs to continue involvement in activities that positively impact policies, programs, services and supports regarding children with special health care needs.

3. Employment of State Parent Consultant and Regional CSHCN Center Parent Coordinators--Infrastructure Building Services--CSHCN

The continued employment of parent consultants at all five Regional CSHCN Centers, parent consultants at the First Step Hotline, and the support of a CPL in each of the counties is continuing throughout 2005. The Medical Home Initiative assures a family centered perspective.

4. Participation of families on advisory committees to the MCH and CSHCN Program--Infrastructure Building Services--CSHCN

Parents continue to be utilized in a variety of advisory capacities including parent partners on the Medical Home Practice Teams, parents serving as advisors to the Newborn Screening Program, Early Hearing Detection and Intervention Project, Birth Defects and Surveillance Program, and MCH Advisory.

5. Participation of families as active partners in the Wisconsin Medical Home Initiative--Infrastructure Building Services--CSHCN

Parents continue to act as partners on the primary care practice teams as we continue to develop Medical Homes within Wisconsin.

6. Collaboration on the implementation of a Family to Family Health Information Center grant with Family Voices- Population-Based Services--CSHCN

In 2005, the CSHCN Program continues to be actively involved in the implementation of activities related to this grant including the development of a training and lead trainers regarding health benefits.

7. Coordination with Family Leadership and Support- Population-Based Services--CSHCN

Title V staff work closely in partnership with a wide variety of Family Leadership and Support Programs and/or Initiatives to develop, plan and implement activities related to families. Coordination occurs with parent organizations such as Wisconsin Family Voices, Wisconsin Family Ties, FACETS, Parents as Leaders and Parents in Partnership Training Initiative, Family Action Network and the Parent to Parent Matching Program.

c. Plan for the Coming Year

1. Financial support to Parent Leaders--Population-Based Services--CSHCN

Financial support will be provided to Parent Leaders to continue involvement in activities that positively impact policies, programs, services and supports regarding children with special health care needs.

2. Employment of State Parent Consultant and Regional CSHCN Center Parent Coordinators--Infrastructure Building Services--CSHCN

A statewide Family Centered Care Consultant (FCCC) will work closely with a strong local parent network consisting of parents at each of the five Regional CSHCN Centers, parent specialists at the First Step Hotline, and Parent Leaders.

3. Participation of families on advisory committees to the MCH and CSHCN Program--
Infrastructure Building Services--CSHCN

Parents will continue to be utilized in a variety of advisory capacities including parent partners on the Medical Home Practice Teams, parents serving as advisors to the Newborn Screening Program, Early Hearing Detection and Intervention Project, Birth Defects and Surveillance Program, and MCH Advisory. A focus group will be conducted to develop strategies to increase participation of parents from diverse backgrounds.

4. Coordination with Family Leadership and Support- Population-Based Services--CSHCN

Title V staff will work closely in partnership with a wide variety of Family Leadership and Support Programs and/or Initiatives to develop, plan and implement activities related to families. Coordination occurs with parent organizations such as Wisconsin Family Voices, Wisconsin Family Ties, FACETS, Parents as Leaders and Parents in Partnership Training Initiative, Family Action Network and the Parent to Parent Matching Program.

In 2006, the CSHCN Program will formalize a relationship with WI Family Voices to provide a newsletter to families, provide training to families across the State, and support parent leaders actively involved in the implementation of activities related to systems of care for CSHCN.

5. Participation of families as active partners in the Wisconsin Medical Home Initiative--
Infrastructure Building Services--CSHCN

Parents will continue to act in an advisory committee as we plan and develop Medical Homes within Wisconsin.